where human beings want to experience pleasure, creativity, knowledge, and recognition—basic needs often ignored and unsupported when it comes to the disability experience.[11]

Prejudices against disability are extremely difficult to overcome because they are built into the environment. Even if one could wave a magic wand and improve everyone's attitudes about disability, the built environment would still remain as a survival of discrimination and an impenetrable barrier to the participation of people with disabilities. For those who doubt the existence of disability discrimination, the built environment should stand as living proof of the social exclusion of the disabled, but attitudes sometimes prove to be as rigid to change as concrete walls, wooden staircases, and cobblestone walkways. When George Lane crawled up the stairs of the Polk County Courthouse the first time and refused to crawl up a second time, he sent a message to the highest court in the land—a courtroom that disabled people have not always been able to reach—about the value of disability experience as evidence, and the Court used that evidence to rewrite history, this time in favor of both critique and emancipation.

Chapter Seven

A Sexual Culture for Disabled People

Sexuality is not a right which must be earned or a possession that must be purchased, but a state of being accessible to all individuals, even those who sometimes have to fight for that access.

—Lucy Grealy

The emergence in recent decades of people who define their identities based on sexual preferences and practices is transforming the landscape of minority politics. Sexual minorities are fighting for the rights and privileges accorded to majority populations on many legal and political fronts. The fight over gay marriage is only the most public and contentious of current struggles for full and equal rights by a sexual minority. Proponents of minority sexual identity attack the neat division between the private and public spheres, the relevance of the traditional family and its institutions of marriage and child-rearing, and the moral certainty that sexuality is better controlled or repressed than set free. Claims that sexuality is a major part of a person's identity, that sexual liberation is a good in itself, and that sexual expression is a civil right crucial to human happiness have led to new conceptions of civic life linked to sex. Jeffrey Weeks argues that attention to sexual identity gives birth to the "sexual citizen." For him, sexual citizenship remedies "limitations of earlier notions of citizenship" (39), focuses attention on "sexualized identities" (38), and blunts "forces that inhibit" the "free, consensual development" of human relationships "in a democratic polity committed to full and equal citizenship" (38). Kenneth Plummer also represents the new sexual identities as a form of citizenship, defining "intimate citizenship" as "the *control (or not) over*

one's body, feelings, relationships: *access (or not) to* representations, relationships, public spaces, etc; and *socially grounded choices (or not) about* identities, gender experiences" (14). Finally, Abby Wilkerson notes that oppressed groups tend to share the experience of sexual repression, explaining that sexual agency is central to political agency and that "sexual democracy should be recognized as a key political struggle" (35).[1]

The emphasis on control over one's body, access to public spaces, and political agency will sound familiar to disability-rights activists. Disabled people have long struggled to take control of their bodies from medical authorities and to gain access to built environments and public institutions apparently designed to exclude them. Like the sexual minorities described by Weeks, Plummer, and Wilkerson, disabled people experience sexual repression, possess little or no sexual autonomy, and tolerate institutional and legal restrictions on their intimate conduct. Moreover, legal and institutional forces inhibit their ability to express their sexuality freely and to develop consensual relationships with sexual partners.

It would be an exaggeration to define the oppression of disabled people exclusively in the sexual context; not many people with disabilities consider themselves a sexual minority. Nevertheless, I want to argue that disabled people do constitute a significant sexual minority and that recognizing their status as sexual citizens will advance the cause of other sexually oppressed groups. "Sexuality is often," Anne Finger explains about people with disabilities, "the source of our deepest oppression; it is also often the source of our deepest pain. It's easier for us to talk about—and formulate strategies for changing—discrimination in employment, education, and housing than to talk about our exclusion from sexuality and reproduction" (1992, 9). The facets of my argument are multiple, but most of them rely on the power of disability as a critical concept to defamiliarize how we think currently about sex. First, thinking about disabled sexuality broadens the definition of sexual behavior. Second, the sexual experiences of disabled people expose with great clarity both the fragile separation between the private and public spheres, as well as the role played by this separation in the history of regulating sex. Third, co-thinking sex and disability reveals unacknowledged assumptions about the ability to have sex and how the ideology of ability determines the value of some sexual practices and ideas over others. Finally, the sexual history of

disabled people makes it possible to theorize patterns of sexual abuse and victimization faced by other sexual minorities.

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School Achievement Reports Often Exclude the Disabled
By Diana Jean Schemo

The first time Tyler Brenneise, a 10-year-old who is autistic and mildly retarded, took the same state achievement tests as California's nondisabled children, his mother, Allison, anxiously awaited the results, along with the state report card on his special education school, the Del Sol Academy, in San Diego. But when the California Department of Education issued its annual report on school performance several months later, Del Sol Academy was nowhere to be found. Ms. Brenneise wrote state officials asking why. "They wrote back," she said, "that the school doesn't exist."

That is because San Diego labels Del Sol a program, not a school, said Karen Bachoffer, spokeswoman for the San Diego schools. And like most other states, California does not provide report cards for programs that educate disabled children.

"He doesn't count," Ms. Brenneise said. "He's left behind."

The problem is not confined to California. Around the country, states and school districts are sidestepping the spirit, and sometimes the letter, of the federal No Child Left Behind Education Act when it comes to recording their successes and failures in teaching disabled youngsters. . . .

My argument will hinge on what I call the "sexual culture" of people with disabilities. This phrase is meant to set in motion a process of defamiliarization directed at experiences so intimate and unspoken, so familiar and yet mysterious, that few people will discuss them. These experiences are bundled under what is colloquially called a "sex life"—a term I contrast heuristically to "sexual culture." Sexual culture refers to neither gender assignation nor sexual preference, although obviously they are components of sexual being. Sexual culture references the experience of

sex itself—pure, impure, and almost never simple. By sexual culture, I mean to suggest two ideas about how disabled sexuality disrupts the notion of a sex life: first, sexuality assumes a larger role in the quotidian life of people with disabilities than the usual phrase *sex life* indicates; second, the idea of a sex life is ableist, containing a discriminatory preference for ability over disability. Being able-bodied assumes the capacity to partition off sexuality as if it were a sector of private life: that an individual *has* sex or a sex life implies a form of private ownership based on the assumption that sexual activity occupies a particular and limited part of life determined by the measure of ability, control, or assertiveness exercised by that individual. People with disabilities do not always have this kind of sex life. On the one hand, the stigma of disability may interfere with having sex. On the other hand, the sexual activities of disabled people do not necessarily follow normative assumptions about what a sex life is. Neither fact means that people with disabilities do not exist as sexual beings. One of the chief stereotypes oppressing disabled people is the myth that they do not experience sexual feelings or that they do not have or want to have sex—in short, that they do not have a sexual culture.

Two cautions must be remarked before I undertake an extended argument about the sexual culture of disabled people. First, the distinction between sex life and sexual culture does not turn exclusively on the issue of privacy. While it is true that disabled people sometimes lack privacy for sex, their situation is not wholly unique. Gay, lesbian, bisexual, queer, and transgendered people also suffer from a lack of sexual privacy, and economic resources may determine whether people have sex in private or public. Crowded housing situations, for example, are as offensive to the conception of private sexual expression as healthcare facilities. The distinction between sex life and sexual culture relies not on privacy but on access as defined in a disability context: sexual culture increases access for disabled people not only by breaking down the barriers restricting them from sexual locations but also by bringing sexual rights to where they live. Second, the idea of sexual culture strips away what one might call the existential connotations of a sex life. Existentialism posits that identities are constructed by ourselves for ourselves, that all values are subjective, that we are responsible for our choices, and that we are condemned to be free. The notion of sexual culture relies on different presuppositions about identity. I define sexual identities as theory-laden constructions, combing

both objective and subjective values, used by individuals to make choices, to test the consequences of their actions, and to explore the possibilities and responsibilities of their sexuality. Sexual culture is designed as a concept to provide a deeper, more sustained idea of how sex and identity interconnect by resisting the partitioning and privatization characteristic of a sex life. It means to liberate sex, allowing it to overflow the boundaries of secured places and to open up greater sexual access for people with disabilities.

No Walks on the Beach

I am looking for an intelligent, literate woman for companionship and, perhaps, sexual play. I am, as you see, completely paralyzed, so there will be no walks on the beach.

—Personal ad

Sex always happens somewhere. We go to certain places to fall in love or to have sex. A sex life, perhaps to our disappointment, tends to occur in the same places—the bedroom, hotels, automobiles, health clubs, baths, and so on. Sex will not happen if we do not have access to such places or if we cannot return to them once we discover that they permit sexual activity. If sex is walking together on the beach, if it is running across a field of flowers to meet in an embrace, what is the nature of sex apart from the ability to walk or to run? If a person's wheelchair gets stuck in the sand or if low vision makes it uncomfortable to dash across a field, does it mean that this person will have little chance of having sex? Clearly, people who do not do these things or go to these places manage to have sex, but that is not exactly the point. The point is to ask how the ideology of ability determines how we think about sex.

The ideology of ability represents the able body as the baseline of humanness. Absence of ability or lesser ability, according to this ideology, marks a person as less than human. The preference for ability permeates nearly every value in human culture, including the ability to have sex. In fact, sex may be the privileged domain of ability. Sex is the action by which most people believe that ability is reproduced, by which humanity supposedly asserts its future, and ability remains the category by which sexual

reproduction as such is evaluated. As a result, sex and human ability are both ideologically and inextricably linked. Mark O'Brien recounts a story about the belief that the inability to have sex robs the disabled person of human status:

> We watched a movie about disability and sexuality. The movie consisted of four or five able-bodied men joking and laughing about how they once lugged their crippled friend up a flight of stairs to a whorehouse. . . . After the movie, a doctor talked about disability and sexuality. . . . I will always remember his closing line: "You may think you'll never have sex again, but remember . . . some people do become people again." (O'Brien and Kendall 2003, 80)

The doctor is speaking loosely about sex and membership in the human community, but he employs a widespread prejudice used against those who have lost human status along with the ability to have sex. What is it about sex that bestows human status? Barbara Waxman Fiduccia argues that disability assumes the characteristic of a sexual perversion because disabled people are thought unable to produce "quality offspring" (168–69). It is reproduction, then, that marks sexuality as a privileged index of human ability. In fact, the ideology of ability underlies the imperative to reproduce at many levels, establishing whether an individual supposedly represents a quality human being. First, sex appeal determines the opportunity to have sex. The greater a person's capacity to attract partners, the more opportunities to have sex. Second, a person must be able physically and mentally to have sex. Third, a person must be able to reproduce, to be either virile or fertile. To fail to be able to reproduce is somehow to fail as a human being. Finally, successful reproduction is thought to pass our essential abilities and qualities to our children. The predominant assumption is that what we are will be visited upon our children. If a person does not measure up to society's ideas about ability, that person's opportunities to have sex will be limited. People with disabilities share with gay men and lesbians the suspicion by majority populations that they cannot, will not, or should not contribute to the future of the human race. They will not reproduce, but if they do, the expectation is that the results will be tainted. Social stigma would have little impact on sexual behavior if it were not for the fact that ability represents the supreme measure of human choices, actions, thoughts, and values.

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When Gender Isn't a Given
By Mireya Navarro

The moment after labor when a mother hears whether her new child is a boy or a girl, Lisa Greene was told she had a son. She named her baby Ryan and went home. Ms. Greene learned five days after the birth that her baby was really a girl.

Doctors who ran tests diagnosed congenital adrenal hyperplasia, a condition that, put simply, can make baby girls' genitals look male. As the young mother struggled to get over her shock, to give explanations to relatives and put away the blue baby clothes, she also had to make a decision: whether to subject her daughter to surgery to reduce the enlarged clitoris that made her look like a boy, or leave it alone.

Thus Ms. Greene, a 26-year-old cashier in East Providence, R.I., was thrown into a raging debate over a rare but increasingly controversial type of cosmetic surgery.

For decades, parents and pediatricians have sought to offer children whose anatomy does not conform to strictly male or female standards a surgical fix. But the private quest for "normal" is now being challenged in a very public way by some adults who underwent genital surgery and speak of a high physical and emotional toll.

Some of them gave tearful testimony at a hearing last May before the San Francisco Human Rights Commission, which has taken up the surgeries as a human rights issue and is expected to announce recommendations before the end of the year. They spoke of lives burdened by secrecy, shame and medical complications: some said the surgeries robbed them of sexual sensation and likened the procedures to mutilation; others said they were made to feel like freaks when nothing was really wrong with them. . . .

The concept of a sex life encapsulates many of the ways in which the ideology of ability distorts current attitudes about sexuality. At the most superficial level, a sex life is described almost always in the context of health. A sex life must be, first and foremost, a healthy sex life, and the more healthy a person is, the better the sex life is supposed to be. Whence

the imperative in today's culture to "work on" one's sex life, to "improve" or "better" it, to do special exercises or adopt a particular diet for it, "to spice it up"—all for the purpose of discovering "the ultimate pleasure." These and other catch-phrases attend the commodification of sex as healthy and satisfying, but the connection between a sex life and ability runs deeper than cliché expressions. When disability is linked to sex, it becomes a clinical matter in which each disability betrays a particular limitation of sexual opportunity, growth, or feeling. The literature on sex and disability recites a litany of limitations for each category of impairment. The blind have trouble with sex because it centers supposedly on a visualization of the body as integral whole, and lacking sight, they cannot visualize what a body is (Hamilton 239). The mobility impaired and paralyzed are apparently cut off from sources of information about sex from peers, and their sexual development remains stunted (Shuttleworth 265–66). Because of language delays, deaf people are believed to be emotionally and sexually immature, living without the language tools needed to meet the high standards of communication required for sex (Job 264, 266). Disabled women are said in the desire to be normal to tolerate sexism and objectification (Fine and Asch 29–30). In general, people with disabilities are thought to suffer from distorted body images, considering themselves ugly, and they do not feel at home with typical gender roles.

While many of these problems ring true, they also expose the difficulty of conceiving of sexuality in ways that do not reproduce the ideology of ability. Because a sex life depends on ability, any departure from sexual norms reads as a disability, disease, or defect. Moreover, the equation runs in the other direction as well: disability signifies sexual limitation, regardless of whether the physical and mental features of a given impairment affect the ability to have sex. The fusion between ability and sexuality appears foundational to the nature of humanity, so much so that any attempt to unfuse them is considered a threat to the human race itself. Eugenics and the human genome project design futures for humanity on the basis of the desire to eliminate transmissible traits linked to disability, but the fear of disability also stymies intimate romantic relations, even when reproduction is not an expectation in the relationship. Many people in the disability community are still waiting, as Corbett Joan O'Toole explains, to hear a story where a man or woman who chooses to be lovers with a disabled person is congratulated by family and friends for making

a good choice (2000, 217). What sea change in current scientific, medical, political, and romantic attitudes would be necessary to represent disabled sexuality as a positive contribution to the future? To reconceive sexuality apart from ability, it would be necessary to imagine the sexual benefit of a given impairment, to claim and celebrate it as a sexual advantage—a paradoxical but necessary thought.

Private Parts in Public Places

I was very shy before my accident. Dealing with lots of nurses doing extremely personal things to you—sometimes in front of other people—knocks off your shyness.
—A QUADRIPLEGIC

If people with disabilities are to develop a sexual culture, they will need to access safe spaces where they may develop new erotic theories and modes of being. A major obstacle to this project is the separation between the private and public spheres and the history of this separation in regulating sexuality in general and disabled sexuality in particular. Feminists identify the private/public split as a source of gender and sexual oppression because it often reifies gender differences and disempowers women. First, men have more power than women to draw the lines between private and public life. Second, men often use this power to maintain or to increase their advantage over women, forcing them into dependency, using privacy to conceal sexual violence, and stifling any attempts by them at political protest. Because the state is reluctant to enter the private sphere, women are imprisoned there, made vulnerable to abuse by domestic partners and given the status of second-class citizens. Early feminists thought the solution to patriarchy was to destroy the separation between private and public life—whence the banner cry "The personal is political." More recently, they have argued that the private/public distinction is a double-edged sword: it gives political power to men, but it also maintains spheres of intimacy traditionally valued by women.

Disability studies supports the feminist argument that the private/public split is responsible for political oppression, while deepening the perception that privacy is abandoned at a terrible cost. The experience of

disabled people with the medical model has been key to this perception. At first glance, the doctor's office would seem to provide only one more example of patriarchy at work. No doubt it does. However, the medical establishment maintains the separation between men and women not by matter of difference but degree when compared to the separation between the disabled and nondisabled. The medical model thrives by sustaining an essential difference between nondisabled and disabled people, defining disability not as a flourishing of biological diversity but as an individual defect that medical professionals cure or eradicate in order to restore a person to the superior state of health required by the ideology of ability. For twenty-first-century medicine, then, it matters only a little whether you are a man or a woman when a surgeon reaches into your body and puts a hand on an internal organ. Nor does it matter a great deal whether the doctor is male or female. The organ will be removed if the doctor thinks it should, whether the procedure has been discussed or not. Male and female doctors alike have experimented on me, and I never knew that experimentation was happening until later, sometimes years later. Rare is the doctor who explains procedures, let alone allows patients to question them. There seems to be no protected realm, no private sphere, into which the medical establishment cannot reach.

If an urgent task is to protect privacy, while attacking its use in the oppression of women, minorities, and people with disabilities, there is no better place to begin than with the medicalization of the private sphere. My focus is on questions of sexuality, of course, but it should be noted that issues of power are never far away because the medical prohibition of disabled sexuality demonstrates that the private/public split uses sexuality as an adjunct to power. The medicalization of the private sphere produces, particularly when linked to sex, a set of exclusionary practices unlike any other, transforming the traditional division between private and public life in surprising ways and discarding practices valued and protected in almost all other cases. For this reason, the critique of the medical model in disability studies represents a genuine resource for rethinking the separation between private and public life. Disability studies may also offer explanations about why sexual minorities and their intimate practices threaten many people at this moment in time.

One way to retheorize the private/public split is to look at the impact of medicalization on economic class. Money buys privacy, and many practices, legal and other, follow the money. Clubs using private money need not obey antidiscrimination laws. Customers who pay more win the right to have their own private spaces carved out of the public domain. For example, first-class and business-class passengers on airlines routinely have bathrooms reserved only for their use and into which coach passengers may not go. Property rights based on economic advantage also determine privacy laws. Indeed, laws against trespassing are a primary support to the right to privacy. The spaces that one owns or rents define the places where private things are permitted; if one tries to do private things in public—that is, commonly owned places—police intervention and arrest are more likely to occur. Private dwellings are protected against forced entry and search, unless there is a warrant, while people who live on the street are almost always vulnerable to search and seizure. Public restrooms, rest stops, and community parks have enforced vagrancy and decency laws designed to control economically disadvantaged people and other populations thought marginal. Without the money to buy privacy, there is little protection against public exposure and its invasive extensions. Presumably, then, the economic basis of privacy should be hard to disrupt. If money maintains the separation between private and public life, those with economic means have a strong interest in preserving the hold of money over privacy.

Here the presence of disability exposes the fragility of the traditional separation between private and public because economic factors do not obtain for disabled people in expected ways. Medicalization opens privacy to assault, and while economic privilege may make this assault less intrusive, it does not eliminate it. A private room in a hospital, no matter how expensive, is not like a hotel room, although it is leased for a certain period. No "Do Not Disturb" sign, controlled by a patient, will ever hang on the doorknob. Doctors, nurses, aides, and janitorial staff enter and exit at will. Despite the persistent fantasy that doctors, nurses, and nurse assistants provide sexual services, hospital trysts and erotic sponge baths are not part of their job descriptions. In fact, their professionalization hinges on being able to invade privacy while divorcing that invasion from its sexual associations. It may be acceptable, Dominic Davies explains, for male patients to get an erection when having their penis washed, but "consensual, vigorous washing is seen as forbidden" (183–84). As long as medical staff *act* professionally, they do not consider themselves responsible for

sexual side effects, and yet they cross erotic boundaries constantly, with little real regard for the consequences of their actions. Patients in medical institutions are simply not considered able-bodied, and they do not possess the same rights as nondisabled staff. It is as if sick or disabled individuals surrender the right to privacy in exchange for medical care, even though caregivers work for them. "The difference between those of us who need attendants and those who don't," Cheryl Wade claims, "is the difference between those who know privacy and those who don't" (88).

Group homes and long-term care facilities purposefully destroy opportunities for disabled people to find sexual partners or to express their sexuality. Even though inhabitants in group homes pay rent for their rooms, the money buys no functional privacy or right to use personal space (Stoner). The staff usually does not allow renters to be alone in their room with anyone of sexual interest. Renters are subjected to intense surveillance, their activities entered in the day log. In many care facilities, staff will not allow two people to sit together alone in the same room. Some facilities segregate men and women. Add to these restrictions the fact that many people with disabilities are involuntarily confined in institutions, with no hope of escape, and the enormity of their oppression becomes palpable. The intimate lives of disabled men and women, as O'Toole phrases it, are "monitored, documented and discussed by others" (2000, 220). Medical authorities make decisions about access to erotic literature, masturbation, and sexual partners.

The unequal power relations between staff and patients encourage sexual abuse. We are only beginning to gather data on the sexual abuse of people with disabilities, but initial statistics indicate that the incidence of abuse is high (Ward 1349), perhaps two to ten times more than the experience of the nondisabled population (Kaufman et al. 8; Shakespeare 1999, 63). It is puzzling that paralyzed women are especially vulnerable, given that disabled women are not considered sexually attractive by mainstream society, until a closer look is given to the conditions of abuse. A woman unable to leave her bed is a woman always in bed, and conventionally a bed is a sexual site. Paralysis is also pictured easily as sexual passivity or receptiveness—an invitation to sexual predictors, since the erotic imagination thrives on cliché positions and gestures. No wonder paralyzed women who cannot get out of bed worry about imagining themselves as rape victims, even when engaging in consensual sex (Westgren and Levi 311, 314).[2]

Not surprisingly, the depersonalizing effects of medicalization often wound the psyches of disabled people, inducing feelings of worthlessness and sexual shame. O'Brien recounts how nurses made jokes in front of him about his involuntary erections, saying things like "Looks like someone's having a good time" (O'Brien and Kendall 2003, 45). On numerous occasions, therapists engaged in sexual banter and teasing about intimate parts of his body (70–73). Medical staff place patients on bedpans in public, sometimes forgetting about them for long periods of time (O'Brien and Kendall 2003, 23; Johnson 60). Frequently, the abuse is premeditated, representing acts of discipline, payback, or sexual harassment. O'Toole reports that many disabled women experience unacceptable touching by male doctors during medical examinations; they are sometimes publicly stripped and displayed to medical students. These women recount feelings of fear, embarrassment, vulnerability, and shame; they often try to separate themselves from their body, pretending that nothing is happening to them (2000, 218–19). Regrettably, most disabled women and men possess no language to express or discuss these experiences, and little is known about the impact of public stripping and unacceptable touching on their sexual feelings.

Personal choice and autonomy are constitutive features of the private sphere, but once subjected to medicalization, individual preference and self-determination evaporate. When the right to privacy and the medical model come into conflict, a new public sphere, controlled by medical figures and supportive of their authority, appears on the horizon. This medical zone of publicness replaces for people with disabilities everything formerly considered private. It engulfs them in an invasive and discriminatory space where they are viewed exclusively as medical subjects and the most casual stranger feels empowered to touch them, to comment on their disability, and to offer medical advice or charity. The medical model too often makes of the world a hospital where the disabled are obliged to be perpetual patients and the nondisabled have the right to play doctor.

The Erotics of Disability

Because I am so sensitive to touch, so acutely aware of a breeze
on my neck, a ring on my finger, the rib of a sock pressing into

> my ankle, when I choose to participate in sexual contact, my unusually heightened physicality works for and not against me.
>
> —Amy Wilensky

When a people are oppressed, the tendency is to explore the depths of their oppression rather than cataloging the inventiveness of their resistance. As a sexual minority, people with disabilities face many limitations on their intimate behavior and erotic feelings. But, aware of their oppression and defiant of its injustice, they have begun to explore an alternative sexual culture based on the artfulness of disability. The progress has been slow because the fight for access has usually targeted the public sphere where sexuality is not included as part of the agenda or the story. For people with disabilities, "the fight to end discrimination in education, employment and other areas of life," Shakespeare explains, "was all about making personal troubles into public issues. But the private lives of disabled women and men were not seen as being equally worthy of concern" (2000, 159–60). Furthermore, the social construction model favored by critics of the built environment tends to neglect physical aspects of disability related to sexuality (Shakespeare 2000, 162). Consequently, we know much more about the public dimension of disability than about its private dimension; we are at the beginning of a period of sexual investigation for disabled people, where information is scarce and ethnography and sharing of practices need to be pursued.

Nevertheless, there are signs that people with disabilities are claiming a sexual culture based on different conceptions of the erotic body, new sexual temporalities, and a variety of gender and sexed identities. These emerging sexual identities have at least two significant characteristics. First, they represent disability not as a defect that needs to be overcome to have sex but as a complex embodiment that enhances sexual activities and pleasure. Second, they give to sexuality a political dimension that redefines people with disabilities as sexual citizens. It is crucial to understand that sexual citizenship does not translate merely into being able to express sexuality in public—a charge always levied against sexual minorities—but to the right to break free of the unequal treatment of minority sexualities and to create new modes of access for sex. In the case of disabled people, sexual citizenship has particular stakes. Some specific agenda items include access to information about sexuality, freedom of

association in institutions and care facilities, demedicalization of disabled sexuality, addressing sexual needs and desires as part of healthcare, reprofessionalization of caregivers to recognize, not deny, sexuality, and privacy on demand. The rights of sexual citizenship change the conditions of enablement for sexual expression, defying medicalization and redefining privacy according to the sexual needs and desires of dependent and interdependent people.

Sexuality represents, according to Steven Seidman, the last aspect of our humanness not recognized as "socially created" and "historically variable" (2). While certain aspects of the body are not open to transformation, sexual desire and erotic sensation are remarkably flexible. The sexual responses of animals fire on cue instinctively, with few diversions, but human desire, because it relies not on instinct but on symbols, invents new sexual cues all the time. For example, people with paralysis, who have lost feeling in traditional erogenous zones, have found ways to eroticize other parts of their body. They also develop new ways to please their partners by creating erotic environments adjustable to differently abled bodies. As feminists have made clear, normative sexuality requires a distinctive mapping of the body into limited erogenous zones (Irigaray). A parallel geography exists between the places on the body marked for sex and the places where bodies have sex. It is as if the separation between the public and private spheres dictating where we may or may not have sex also maps the body according to zones where sexual feelings do or do not reside. Although it is considered kinky to have sex in out of the way places, it does not usually cross one's mind to summon sexual feelings in places on the body not already demarcated by them. Andrew Vahldieck adds a particularly vivid and thoughtful account to the literature on sex after spinal cord injury about the erotics of the disabled body:

> There's a bumper sticker that proclaims, "Quads Make Better Lovers" and perhaps it's true. One positive by-product of adapting to a disability is having to learn to go with the flow of experience, both mentally and physically. After severe spinal injury, one must begin again, and this includes developing alternate sense faculties. My erotic self need not be solely localized at the tip of my cock, where I've lost much sensation; I have learned that other areas of my body can be erotically sensitive and responsive. Sensation is mobile. My passion, desire and heat can be creatively restrained or refocused on

> more sensitive areas: ears, lips, neck, shoulders. In doing so, I can transfer sensual feeling into areas where sensation is diminished.
>
> Just as important has been learning to free myself from a preoccupation with my own pleasure. To give myself over to my partner. To slow down, not because I'm disabled and have to, but because I want to. This has proved crucial, paradoxically, to building up my own libidinous momentum. By relaxing into a quiet, tender space while stroking and touching my lover, I can engage vicariously in her enjoyment and stimulation so intensely as to share in her—and expand upon my own—felt pleasure. How curious that pleasing women orally has never been held as a form of manly sexual expression. Speaking as a man labeled "severely disabled," this may truly be considered a high and most subtle erotic art.

Disabled sexuality not only changes the erotics of the body, Vahldieck infers, it also transforms the temporality of lovemaking, leaving behind many expectations and myths found in normative sexuality. For example, in the same way that narrative temporality has a beginning, middle, and end, normative sexuality requires beginning, middle, and end points. This is especially true of penetrative sex. Penetration has a preparatory phase, a period of sustainment, and a climax—all designed to prop up the physiognomy of the penis. One gets it up, gets it in, and keeps it up for as long as possible, until one loses it. Penetrative sex figures as a race against fatigue—a performance with a beginning, middle, and end. It also smacks of the assembly or production line, where part after part is added until the product is finished. The dependence of sex on penetration, incidentally, represents one reason why people tend to partition their sex life from everyday existence. Because the temporal phases of penetrative sex are so indelible, its narrative seems relatively autonomous, and it is easy to think of it as an activity apart from all other facets of life.

Because disabled people sometimes require advanced planning to have sex, their sexual activity tends to be embedded in thinking about the day, not partitioned as a separate event. Among disabled people, the so-called sex act does not always qualify as an action or performance possessing distinct phases such as beginning, middle, and end. Moreover, the myth that sex must be spontaneous to be authentic does not always make sense for people who live with little privacy or whose sexual opportunities depend on making arrangements with personal attendants. Rather, dis-

abled sexuality has an ebb and flow that spreads it out among other activities, and its physiognomy does not necessarily mimic conventional responses of arousal, penetration, or orgasm. "I used to get stuck, needing orgasm, needing penetration, etc.," one woman explains. "Now, my sexuality has matured. . . . For example, one of the greatest highs I get (full-body orgasms? or spiritual-like orgasms?) is from having my neck bit" (Kaufman et al. 126). Some people without bodily sensation report experiencing mental orgasms when engaged in kissing, verbal play, or sexual fantasy. Others remark that sexual pleasure grows more intense with the advent of disability, owing either to physical changes or to a greater awareness of their body: "Since I became paralyzed in both legs I have noticed that I have varying kinds of orgasms, depending upon the situation. For example, when I play with myself and rub my clit a certain way my orgasms are much more intense. Sometimes my leg will go into spasm and my crotch feels tingly" (Kaufman et al. 52).

A crucial consideration for people with disabilities is not to judge their sexuality by comparison to normative sexuality but to think expansively and experimentally about what defines sexual experience for them. Sex may have no noticeable physical signs of arousal or may not conclude with an orgasm. When touching is involved, the places being touched may not be recognizable to other people as erogenous zones, which makes sex in public possible and a lot of fun. Sex may extend beyond the limits of endurance for penetrative sex, resembling slow-dancing instead of the twist. It may seem kinky by comparison to what other people are doing. According to O'Toole, disabled sex often surprises a person's community, no matter how radical. For example, in Boston in the mid-1990s, Connie Panzarino marched in a Gay Pride parade with a placard reading, "Trached Dykes Eat Pussy All Night Without Coming Up for Air." That a woman with little movement below the neck could be the active partner in sex and use her disability to enhance her partner's pleasure stunned and shocked people. "This disabled woman," O'Toole notices, "was using her disability as an advertisement for a sexual partner. She was appealing to partners who like extended oral pleasure. She was turning her apparent severe disability into a distinct sexual advantage" (2000, 220–21). O'Toole also mentions an account given by a lesbian amputee about enhancing the pleasure of her partners: "Can I just say that my two leg stumps make fabulous sex toys. I really think my amputated body is tailor-made for lesbian sex: I can

crawl on top of my lover and grind my leg into her cunt in ways that I couldn't if I had 'real' legs. Having my little stumps gives me much more freedom of motion and I can get closer, deeper into her that way. Plus, pushing myself into her and away from her and into her again, moving my hips and legs against/on her body is the closest I have come to slow-dancing in years and I love it" (2000, 215).

Disabled people may advance a different sexual geography both for the body and for the places where bodies express their sexuality. Just as disabled persons may change places on the body not usually associated with sexual feeling into erogenous zones, they reorganize places inhabited by bodies as locations for sexual culture. Citizenship rights tend to be practiced in certain locations—polling places, town centers, courtrooms, and so forth—and these locations are not always accessible to people with disabilities. Sexual citizenship suffers from the same restrictions, but here the goal is not necessarily to make the built environment more accessible, although it is an important goal, but to bring rights to the places where disabled people want to have sex. Privacy on demand, for example, could transform a hospital room into a safe space for sexual activity, avoiding the difficulties described by this disabled person: "Even though I am often by myself, I never know when someone will walk in on me. I may look back and think, 'I've just had half an hour to myself, I could have masturbated,' but the time wasn't guaranteed. It isn't really my time" (Kaufman et al. 114). Unfortunately, we are still at a stage where there are more negative illustrations of how rights of sexual citizenship fail than positive examples of how they might work. Nevertheless, people intent on having sex find fugitive places to commingle: "Accessible toilets are FAB. . . . One can get pushed in there by a lover and everyone thinks, 'Isn't that sad, someone needs to wipe their bum,' and you can shag away in private and then come out and no one has a clue as to what really went on! It's liberating and definitely one of the few perks of being a wheelchair user!" (Kaufman et al. 130–31). Embracing greater sexual diversity is key to the rights of disabled people, and it might have unanticipated benefits for thinking about sex in general. As one woman explains it, "if you are a sexually active disabled person, and comfortable with the sexual side of your life, it is remarkable how dull and unimaginative non-disabled people's sex lives appear" (Shakespeare 2000, 163).

New formations of gender and sexed identity may be the final frontier of sexual citizenship for people with disabilities. Although present currents on the Left and Right wish to abolish identity entirely, especially identities connected with sickness and perceived weakness, gender and sexed identities make sexuality present as a mode of being not easily closeted away or partitioned into isolated temporal and spatial segments. Claiming an identity based on sexual culture thrusts one's minority status into the foreground, politicizes it, and creates the opportunity to clarify sexual needs and desires. It also resists the closeting of gender and sexuality central to Western attitudes about sex. It may be especially valuable for people with disabilities to assert sexed identities, since Western attitudes seem married to the argument that "sex is sick," giving people perceived to be "sick" extra purchase in making counterarguments.

Apart from the urgency of political resistance, it may simply be the case that different identity formations suit people with disabilities better. They often complain that conventional notions of male and female or straight and gay do not apply to them (Shakespeare 2000, 163), and it is fairly obvious that their sexual practices depart from many of the founding myths of normative sexuality. Disabled people do not embody gender in "natural" ways because gender stereotypes do not allow it. "It's like I don't have any maleness," one disabled man complains (Shuttleworth 272). Certain disabilities appear to offer specific gender limitations. Men with cerebral palsy cannot touch or hug their female partners in the ways to which they are accustomed (Shuttleworth 269). Blindness changes sexual flirtation from afar between men. But another person puts a positive spin on flexible gender identity: "Why should men be dominant? Why should sex revolve around penetration? Why should sex only involve two people? Why can't disabled people be assisted to have sex by third parties?" (Shakespeare 2000, 163). O'Toole notes that no lesbian equivalent of the missionary position exists, and that partners are not obliged to have orgasms in the same position at the same time (2000, 213). Disabled sexuality embraces a similar flexibility. The sexed identities of disabled people are of value to all sexually active people, Shakespeare claims, because they allow for a continuum of sexual practices and encourage a greater willingness to embrace diversity, experimentation, and alternative sexual techniques (1999, 58).

Conclusion

If we are to liberate disabled sexuality and give to disabled people a sexual culture of their own, their status as sexual minority requires the protection of citizenship rights similar to those being claimed by other sexual minorities. The challenge of sexual citizenship for people with disabilities is great because they remain one of the largest unrecognized minority populations, little awareness exists about the manner of their oppression, sex is a taboo subject for everyone in general and for disabled people in particular, and the unquestioned embrace in most societies of ability as an ideology denies participation in the public sphere to those not deemed quality human beings. Integral to sexual citizenship for people with disabilities is the creation of a safe space with different lines of communication about disabled sexuality; they need in effect to invent a new public sphere receptive to political protest, public discussion, erotic association, and the sharing of ideas about intimate practices and taboos, erotic techniques and restrictions, sexual innovation and mythologies.

An illustration of one space of exemplary safety and communication is found in the experience of disabled parents who adopt children with disabilities. It is exemplary both because it seems not to rely on a reproductive politics so difficult to untangle from the ideology of ability and because it establishes communication lines between the generations that do not obey the sexually repressive laws often obtaining between parent and child. How strange are the sanctions by which parents limit in children the very sexual behaviors that gave birth to them, as if parents wish secretly that their children had never been born and will produce no offspring. Better to develop lines of communication between parent and child and sibling and sibling that assist sexual expression and happiness. If one objective of disabled people is to build a new sexual culture, it is crucial for them to pass information from one generation to another about gender and sexed identities. Disabled children, then, are key to the future of disabled sexuality.

Disabled children, unlike nondisabled ones, cannot rely necessarily on peers for information about sex, since peer groups represent more likely sources of discrimination and intolerance. Disabled parents must be proactive about their disabled children's sexual concerns because the prejudices against disabled sexuality are so strong. O'Toole and Doe report that disabled mothers have come together to initiate a new sexual culture that teaches disabled children to love and to care for their bodies. The main strategy is to pass on positive sexual values to children and to teach them how to resist negative stereotypes about disabled sexuality. A consensus statement by 614 women from eighty countries captures the essence of their philosophy: "We want a disability sexual culture focused on our entitlement to pleasure and love, understanding the advantages of possessing bodies and functions different when compared to women's majority culture" (O'Toole and Doe 99). The result is a radical transformation of the parent-child relationship, creating a positive atmosphere for sexual expression, providing useful advice about gender identity and reproductive care, and promoting sexual self-esteem in children.

The project of educating disabled children about sexuality, however, is not without its dangers. Primary is the resistance to viewing the parent-child relationship in a sexual light, even an educational one. One mother, for example, was worried that her daughter was trying but failing to reach her genitals for masturbation; she wanted to "facilitate her daughter's sexual independence" without interfering with her sexual expression (O'Toole and Doe 98). But the mother found no sources of advice on the topic, and other parents cautioned her not to raise the issue with medical professionals, unless she wanted to be accused of sexual abuse. Disabled sexuality has long been closeted, and bringing it to light carries a serious threat, one often matched by the threat of violence. Until a fundamental change occurs, those who would seek to advance a sexual culture for disabled people will remain at risk, whether from outright violence or more subtle forms of aggression.

In the clash of the culture wars, some people have argued for a monoculture where we abandon all identities except nationality, while other people argue for a multiculture where we embrace many identities—racial, ethnic, gendered, national, and sexed. The call for a disability culture in general and a sexual disability culture in particular will arouse, no doubt, the anger of the first group and garner, with luck, the support of the second. But the stakes in the emergence of a sexual culture for disabled people are greater than the dispute between these two political factions. The stakes concern questions about fundamental rights expected by all

citizens in a democratic society: freedom of association and intimate companionship, authority over their own body, protection from violence, abuse, and oppression, and the right to pursue a sexual future of their own choosing. Because every citizen will become sooner or later a disabled citizen, the struggle of people with disabilities for sexual rights belongs to everyone.

Chapter Eight

Sex, Shame, and Disability Identity

With Reference to Mark O'Brien

I began to feel that I was a bad, filthy thing that belonged to the nurses.

—Mark O'Brien, *How I Became a Human Being*

My goal in this chapter is to use the discourse of gay shame as a jumping-off point to investigate further both the sexual culture of disabled people and the power that disability exercises as a critical concept for revising theoretical paradigms. My strategy and pleasure are to pursue this goal with constant reference to the writings of Mark O'Brien, the Berkeley poet, now deceased, who spent all but six years of his life in an iron lung due to polio and whose poetry and journalism represent a vivid testimony to the fusion between the three key terms of this chapter: sex, shame, and disability identity.

Eve Kosofsky Sedgwick, of course, argues that shame has ethical leverage because it manages the threshold between identity construction and erasure (2003, 35–65). Shame promotes a kind of queer identity—an identity in which difference may metamorphose into shared dignity with and ethical sympathy for victimized people. Nevertheless, Sedgwick does not illustrate the capacity of shame to create a new ethics with examples from the gay community. Rather, she uses disability to exemplify shame, whether representing the shared humiliation felt before the "toothless face" of New York's post–September 11 cityscape or her own identification with Judith Scott, the fiber artist with Down syndrome portrayed on the cover of *Touching Feeling*.[1] In fact, Sedgwick's principal technique for il-